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Evaluation of data collected in the first stage within the scope of hemoglobinopathy control program in Turkey's east mediterranean city Kahramanmaraş

Hemoglobinopathy screening in Kahramanmaraş

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Abstract

Aim: This study aimed at determine the frequency of hemoglobinopathy, which is one of the hereditary blood diseases, in Kahramanmaraş. Material and Method: In this study, which has been planned in the descriptive style, the scan records of the couples reported to the Kahramanmaraş Provincial Directorate of Health, Maternal and Infant Health Unit with the purpose of scanning whether they carried hemoglobinopathy prior to getting married between January 2012 and December 2016, have been analyzed retrospectively and the results have been evaluated. Results: According to the records, it has been determined that 68.177 people's scans have been taken in five years in Kahramanmaraş, the scanning rates varied between 70-90% and that 610 women and 573 men have hemoglobinopathy. Between the years 2012-2014, the percentage of people with hemoglobinopathy has been determined as 1.43% and this percentage has been observed to increase to 1.93% in 2015 and 2.50% in 2016. According to the data dated 2016, although there has been a decrease in the number of people who got married and the number of scans prior to getting married, there has been an increase in the number of people with hemoglobinopathy. Discussion: In the scan process carried out prior to marriage in Kahramanmaraş, the rates of carrying hemoglobinopathy have been found similar to the rates in Turkey and the surrounding cities.

Keywords

Hemoglobinopathy Screening; Scanning Prior to Marriage; Frequency of Hemoglobinopathy

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Introduction

In the world, hemoglobinopathy diseases constitute important health problems in 71% of the countries and 3.4% of child mortality below the age of five [1,2]. According to DSÖ data, about 5% of the world population and 7% of pregnant women are affected from hemoglobinopathy disorders [1-4]. In Turkey, since Hemoglobinopathy Diseases (beta thalassemia and sickle cell anemia (SCA) prevalence has increased from 0,3% to the 10% range, it has become an important public health problem [5, 6]. The mortality and morbidity level of hemoglobinopathies are high and their follow-up and treatment are difficult and expensive. Therefore, studies which were initiated in the 1950's in Turkey about hemoglobinopathy with the purpose of reducing the amount of morbidity and mortality related to hemoglobinopathy under the Law on Fighting Hereditary Blood Diseases have gained a significant speed with the publication of Regulation on Hereditary Blood Diseases in 2000, prepared by The Ministry of Health and National Hemoglobinopathy Council. In 2003, the Hemoglobinopathy prevention Program has been initiated in 33 cities including Kahramanmaraş and beta thalassemia centers were opened and the scans of couples were taken before they got married [2,4-6,7-9]. The scanning program covers primarily thalassemia and hereditary blood diseases such as Hemophilia, Sickle Cell Anemia and Erythrocyte Enzyme Diseases [4,5]. As a result of these activities, a reduction up to 87% range has been achieved in the new born patients with beta thalassemia throughout Turkey [6, 9-11].

The most effective method in controlling hereditary diseases which display autosomal recessively inheritance such as thalassemia, is to inform the society about the disease, identify the carriers with public scans, giving consultancy services to the identified patients and prevent the birth of babies with the disease by using prenatal diagnosis methods. Thalassemia has been taken under control, the number of new patients has been reduced and even lowered down to zero in many countries in this manner [5]. In this study, it has been aimed at evaluating the results of the Hemoglobinopathy scans taken for a period of five years prior to marriages in Kahramanmaraş and determining the rate of the carriers.

Material and Method

In this study, the scan records of the couples reported to the Kahramanmaraş Provincial Directorate of Health Maternal and Infant Health unit from February 10 to 25, 2018 with the purpose of scanning whether they carried hemoglobinopathy prior to getting married between January 2012 and December 2016. These records and results have been evaluated retrospectively. Prior to the planning of the study, the health directorate was informed about the study and permission and approval has been received. In Kahramanmaraş, hemoglobinopathy scans are performed for all couples before they get married. The results of scans taken prior to getting married represent the society and give information about the frequency of hemoglobinopathy in the city of Kahramanmaraş. The scan rates in terms of years, demographic characteristics and illness conditions have been analyzed with the SPSS 20 software program and evaluated through numbers and percentages.

Results

In Table 1, the total number of people scanned, scan context and demographic information can be seen. In the province of Kahramanmaraş, the number of people who got married between January 2012-December 2016 successively is: 18.304, 18.036, 15.012, 17.112, 13.720. The rate of scans taken prior to marriage successively is: 92.6%, 89.3%, 87.2%, 87.0%, 70.6%. About 85-95% of the people who were scanned are registered in the province of Kahramanmaraş.

Their age averages range between 27.0±12.3 and 30.0±9.7.

Table 1. Demographic Characteristics

Year	Number of people who got married n	Total number of people who were scanned n	Scan context %		Registered province %		Age (Mean SD)
			Prior to marriage	Other	Kahramanmaraş	Other	
2012	18.304	16.861	92.6	7.4	93.4	6.6	30.0±10.0
2013	18.036	13.011	89.3	10.7	87.7	12.3	29.0±7.6
2014	15.012	12.477	87.2	12.8	90.5	9.5	30.0± 9.7
2015	17.112	15.147	87.0	13.0	84.3	15.7	27.0±12.3
2016	13.720	11.270	70.6	29.4	94.0	6.0	30.0±9.7

In Table 2, the scanning results according to gender are given. It has been determined 242 (1.43%) people (124 female 0.73%, 118 male 0.69%) in 2012; 187 (1.43%) people (111 female 0.85%, 76 male 0.58%) in 2013; 179 that, 242 (1.43%) people (124 female 0.73%, 118 (1.43%) people (77 female 0.61%, 102 male 0.81%) in 2014; 293 (1.93%) people (153 female 1.01%, 140 male 0.92 %) in 2015 and 282 (2.50 %) people (145 female 1.28, % 137 male 1.21%) in 2016 had hemoglobinopathy.

Table 2. Distribution of Hemoglobinopathy Patients according to Gender

Year	Total number of people who were scanned	Number of patients with Hemoglobinopathy	Gender			
	n	n (%)	Women	%	Men	%
2012	16.861	242 (1.43)	124	0.73	118	0.69
2013	13.011	187(1.43)	111	0.85	76	0.58
2014	12.477	179(1.43)	77	0.61	102	0.81
2015	15.147	293(1.93)	153	1.01	140	0.92
2016	11.270	282(2.50)	145	1.28	137	1.21

Four people out of 242 (0.23%) who were diagnosed with hemoglobinopathy in 2012 were determined as carriers of sickle cell anemia, 195 as carriers of thalassemia (1.56%), six as thalassemia patients (0.35%) and 37(0.21%) as being in another hemoglobinopathy patient group. 143 people out of 187(1.09%) who were diagnosed with hemoglobinopathy in 2013 were determined as carriers of thalassemia, six as thalassemia patients (0.46%) and 38 (0.29%) as being in

Table 3. Distribution of Patients with Hemoglobinopathy According to Years

Year	Total	Carriers of sickle cell anemia		Patients with sickle cell anemia		Carriers of Thalassemia		Patients with thalassemia		Other *	
	n	n	%	n	%	n	%	n	%	n	%
2012	242	4	0.23	0	0	195	1.56	6	0.35	37	0.21
2013	187	0	0	0	0	143	1.09	6	0.46	38	0.29
2014	179	0	0	1	0.08	166	1.33	0	0	12	0.09
2015	293	7	0.46	0	0	248	1.63	1	0.06	37	0.24
2016	282	5	0.44	0	0	222	1.96	0	0	55	0.48

*not indicated in data

another hemoglobinopathy patient group. one person out of 179(0.08%) who were diagnosed with hemoglobinopathy in 2014 were determined as carriers of sickle cell anemia, 166 as (1.33%) as carriers of thalassemia, 12 as (0.09%) as being in another hemoglobinopathy patient group. seven people out of 293 (0.46%) which were diagnosed with hemoglobinopathy in 2015 were determined as carriers of sickle cell anemia, 248 as (1.68%) as carriers of thalassemia, one (0.06%) as patient of thalassemia and 37 (0.24%) as being in another hemoglobinopathy patient group. five people out of 282 (0.44%) who were diagnosed with hemoglobinopathy in 2016 were determined as carriers of sickle cell anemia, 222 (1.96%) as carriers of thalassemia and 55 (0.48%) as being in another hemoglobinopathy patient group. (Table 3).

Discussion

Getting scanned prior to getting married is a protective health service in the sense that it prevents children to be born as carriers or having the disease by identifying carrier couples. In this study, it has been determined that scanning rates involving 68.177 people in five years in Kahramanmaraş are between 70-90%. Between the years 2012-2014, it has been seen that while the rate of patients with hemoglobinopathy was 1.43%, this rate increased to 1.93% in 2015 and 2.50% in 2016. According to data dated 2016, although the rates of the number of people who got married and scanning prior to getting married decreased, there has been

an increase in the number of patients with hemoglobinopathy. When this data is analyzed, it is not clear that patients with hemoglobinopathy are among the couples to get married or among other people who were scanned for other reasons. The analysis of data also shows a decrease in the number of marriages and scanning

prior to getting married and an increase in the rate of scanning performed for other reasons. It is considered that the increase in the number of patients and the change in the scanning rates are related to the changes which took place in the demographic structure of Kahramanmaraş caused by the increasing external migration in the recent years.

When the scanning results for the state of the diseases were analyzed in terms of gender, it has been determined as 4.48% for women and 4.21% for men. In both genders, the rate of hemoglobinopathy is close to each other. The purpose of scanning prior to getting married is to prevent the birth of babies with hemoglobinopathy. Therefore, it is important to inform people who are considering getting married and provide consultancy services prior to pregnancy.

In the world, the primary common hereditary blood diseases are thalassemia and sickle cell anemia. Turkey is a region where carriers of thalassemia are seen frequently. In particular, the number of beta thalassemia carriers and density of other hemoglobinopathies are higher in the Mediterranean, Çukurova, Aegean and Marmara regions [4,12-15].

The average rate of carrying thalassemia in general in Turkey is 2.1%, however this rate reaches 10% in some regions. A high number of kin marriages, lack of education-knowledge and high birth rates give rise to birth of children with hereditary blood diseases such as thalassemia and sickle cell anemia in numbers which are higher than expected [11,12, 16]. In the study of the Ministry of Health and National Hemoglobinopathy Council, in which the scanning activities of 377.339 people over the course of five years were evaluated, the average frequency of thalassemia and hemoglobinopathy has been determined as 4.3% and carrying rate of sickle cell anemia has been determined as 10.5% [17].

In the study by Güler et al. (2008), which deals with the scanning of 11.040 people in Kahramanmaraş, the rate of carrying thalassemia has been determined as 2.35% and sickle cell anemia as 0.54% and the researchers have stated that the carrying rate is much lower compared to the rates in general in the other areas of the Mediterranean region due to the characteristics of ethnic structure [16].

In this study, the rate of carrying thalassemia in a period of five years has been determined as 7.5%. This result is lower than the regional average and the results of scans performed for Kahramanmaraş [8,11,16,17]. The rate of carrying sickle cell anemia has been stated as 10% for Çukurova, 8% for Hatay and 6.1% for Içel and surrounding areas [1,5,6,8,10,16]. In a study of 48.126 people scanned in Kahramanmaraş, the frequency of beta SCA has been determined as 0.4% [11].

In this study, the rate of carrying SCA for five years has been determined as 1.13%. This rate is below the regional average. However, the increase in the disease and the carriers should be taken into consideration and it is necessary to provide genetic consultancy services after scanning by taking into account the demographic changes.

Conclusion

In conclusion, although the situation differs from one region to another, hemoglobinopathy diseases constitute an important health problem in Turkey. The thalassemia prevention program is being carried out successfully. However, according to this program, the number of Hemoglobinopathy diseases in Kahramanmaraş has increased especially in the recent years. As a result of the Hemoglobinopathy scans performed prior to marriage, it is suggested to inform carrier couples and to raise public awareness of these diseases through consultancy services related to prenatal diagnosis.

Scientific Responsibility Statement

The authors declare that they are responsible for the article's

scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and human rights statement
All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.

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